What is pain and how do we talk to people about it?

Webinar 20th September 2021

Betsan Corkhill

Lifestyle health coach

A recording of Betsan’s presentation is available at <https://www.dropbox.com/s/ynuil9sruv6n286/WHAT%20IS%20PAIN%20%26%20HOW%20DO%20WE%20TALK%20TO%20PEOPLE%20ABOUT%20IT_RECORDED_1.mp4?dl=0>

I am a former physiotherapist now working as a lifestyle and wellbeing coach mainly working with people with long-term health issues particularly chronic pain. I am a certified Tai Chi trainer

It’s great to see quite a few people who live with pain here tonight. I’m hoping this can be a start of a longer discussion between professionals and patients. I’ll pose some questions along the way that we can discuss at the end. I don’t pretend to have the answers, but I have a few suggestions. I also want to make clear that it’s about what works for the individual living with pain.

The language we use when we talk to people about pain is hugely important for getting across accurate information and for the expectations it creates not only in those seeking our help, but in us too. We should think about our written communication, the posters on the clinic walls, the messages on the clinic answer phone and even about the way you talk to yourself.

 This includes the messages we convey through our body language, the unspoken, unwritten language with which you connect with the person seeking your help, recognising that the language you use is always heard within the context of the relationship you develop with them. This relationship is probably the most important issue.

The words we use can change a person’s future. They can promote a sense of fear, hopelessness and helplessness to set a person down a path of prolonged pain or start them on a journey of hope, wellness and recovery. We also need to consider how much we *talk* in a consultation because it’s as much, if not more, about the *listenin*g.

 Many years ago, Lorimer Moseley said to me, “*Think about what it’s doing to their biology. Think about it in all your interactions and interventions*.” The language we use affects a person’s expectations and changes their biology.

Language and Pain

Is the language we use partly responsible for prolonging pain? I’ve been interested in this question for a few years; as well as stopping the use of language that may harm we need to consider the deliberate use of language to promote change, to promote a sense of safety and healing. We have a few people here tonight who use hypnosis and really understand the power of words and how we can use them to our advantage.

The language used about pain in the clinic and in society is pretty negative. I’ve sat in on many pain management programmes where the clinician will use these, or similar words at, or near the start:

 “There is nothing we can do to cure your pain. We’re here to teach you coping skills.

 It’s about self-management and pacing. Learning to live with pain.”

What does a statement like this do to a person’s expectations of their future? When you hear them you can feel the mood in the room drop like a stone.

 These expectations are hugely important in the modulation of information and the eventual pain that emerges - or not. People hold on to negative beliefs. Nocebo is powerful, and nocebic messages and language tend to lurk in the subconscious and become sources of fear and threat that can lead to a cascade of negative thoughts and more fear, anxiety. Nocebic or poor inaccurate language provides scaffolding for more pain.

But want *is* pain?

Before we can start using the right words we need a clear idea of what pain is, and perhaps more importantly what it is *not.*

 The continued use of the term pain signals is a good example of how we convey an incorrect message when we ourselves don’t understand the subject. The fact that nociception and pain are different is at the core of understanding pain. Nociception starts in the tissues, pain does not. If you don’t feel pain it doesn’t exist, whereas nociception does. Just think about this for a moment - *if you don’t feel pain it doesn’t exist*. This can be a really powerful realisation for people. The term pain signals is still used by clinicians, in articles, books and online information, even on the British Pain Society’s ‘What is pain’ information.

 “Anyone who talks about pain signals is talking neurobollocks”

 Mick Thacker

This quote always makes me smile. When you think about it, it’s absolutely true, isn’t it? The term pain signals is *absolute… neuro… bollocks*. When you know your biology, you know this can’t be true. Pain isn’t carried in some magic package from your knee to your brain. Nerves don’t / can’t transmit pain. The term pain signals also reinforces the belief that there is a linear pathway between a painful body part and the feeling of pain; that pain originates in the tissues – it doesn’t. I’ve been told by people who use it: ‘it’s a term the lay person understands’. I think that’s quite patronising. You’re not educating people if you give them the wrong information

“One of our challenges is that we’re always having to think how we make complex situations simple and how much information we give them so they’re not clouded or confused.”
 Gareth Southgate England Football manager

It’s our job to give accurate information and to find ways of conveying that information in a way that the individual understands and that will be different for each person and their individual story.

“The biggest lesson I’ve learned… at the start I communicated with everyone in the same way… but actually that doesn’t work because we’re all individual, we all respond differently … so the ability to communicate across different levels is important. Having an understanding of their backgrounds, interests and motivations is important. All their stories are so different … the more you can understand your staff and players, the better.”

 Gareth Southgate

As Gareth says, we’re all individual. We all respond differently so the ability to communicate across different levels is important. An understanding of a person’s background interests and motivations is important. All their stories are so different. The more you can understand the people who seek your help, the better. It’s vital you know that person’s story and tailor the language you use so that it’s meaningful to them. There is a big difference between simplifying a message to a point where the information becomes patronising or incorrect, and being able to get complex information across in a simple way.

 “Pain is what a person says it is.”

I’m going to stick my neck out here and go back to this phrase that we used years ago. At the last in-person conference I attended on pain in 2019 one of the speakers put this up on his screen and laughed saying “*Please tell me no-one believes this anymore…anyone here still think this is true?*” Everyone laughed. I so wanted to put my hand up and say ‘actually yes’ and I regretted not doing so because pain is so individual. Even if we have experienced pain ourselves we can never ever know what another person’s pain feels like or know the impact it has on their lives. It will certainly mean something different to you than it does to this patient - and the next - and the next.

 It can disrupt every aspect of life and the impact of that disruption can often be worse than the pain. A relatively mild pain that goes on and on and on unremittingly can drain you to a point where it is much worse than more intense pain that flares from time to time.

Complexity

Of course, there are formal definitions of pain and attempts to divide different pains into categories, but they don’t actually tell us what pain is to the individual. The bottom line is that it’s always a complex mix, heavily dependent on, and influenced by, context. And to complicate things further you have this strange thing called nice pain. That feeling that you ‘know’ is pain but isn’t unpleasant is usually a matter of context: for me pain after exercise or perhaps a vigorous massage of tense muscles. fit into this category

 On the darker side of nice pain, those who self-harm often describe the pain of it as a momentary respite from the awfulness of a life that hurts. A moment of control. Having experienced several months of trigeminal neuralgia last year when dentists were closed, I can understand this desire to experience a different pain – the potential for just a moment of relief. Then you have pain that can exist without suffering…

So what are we trying to measure when we measure pain? Is it actually possible to measure pain, this level of complexity? It’s hard to get your head around all these dynamic, organic, complex systems. You need to get a feel for it - to get it intuitively - rather than try to define it . But I’ve found that people actually cope with knowing that it’s complex and hard to explain. Indeed, they are relieved because it explains why quick fixes or medication don’t work. All of a sudden, things start to make sense when you learn it’s complex.

“Understanding that pain is multifactorial, that it’s not a purely biomedical phenomenon and that I had control over so much that was influencing my pain experience and my suffering was transformative.”

Niki Jones (Pain patient)

We have to persevere with getting this message across.

The term bio-psycho-social was coined to try to capture some of the complexity. It was intended to help us better understand a person in their individual context. Its benefits are that it does remind us of the wider aspect but in reality, but it has resulted in our dividing the whole person into categories and sending people to different specialists who often don’t communicate.

“It chops the patient up into three neat packages.”

 Cabaniss

 “Boundaries are often arbitrary but once some arbitrary boundary exists, we forget

 that it is arbitrary and get way too impressed with its importance.”

Robert Sapolsky 2017

But even when the boundaries were created merely to remind us, we get used to these boundaries and over time we forget that they’re not real

“In Britain in 2018, the NHS is still planned on cartesian lines. Patients literally go through different doors, attend different hospitals, to consult differently trained doctors about their dualistically divided bodies and minds.”

Edward Bullmore

The result is we get silos of fragmented, linear care, with people getting multiple health labels and different treatments by different ‘specialists’. In reality people with complex problems are being turned away from Secondary and Tertiary care because they don’t fit into the criteria of these linear pathways; their issues are too complex. People I work with often have eight or more different disease / condition labels.

“*We’re sorry, you no longer fit our criteria*.”

Think for a moment about what it does to a person when the expert at the end of the line sends you a statement like this in a letter before even seeing you.

 People and pain are messy and the longer you live with pain, the more complex and messier it gets.

“There is no distinction between the liquidity of milk, the whiteness of milk and the nutritious qualities of milk. The consistency, colour and quality of milk are an integrated whole.”

Satish Kumar – Small world, Big Ideas: Activists for change (2012)

We can’t separate out the bio from the psycho or the social. They’re not separate entities, and the irony is it’s all bio anyway…isn’t it? For example, take the psychological and bio interaction (or psychosomatic) as illustrated in this story:

“*Man on drugs trial overdoses*”

This 26-year-old man was taken to A&E. He attempted suicide by taking 29 capsules of an experimental drug obtained from a clinical trial to test a new antidepressant that he was part of. When he arrived at the hospital, he was sluggish, shaking, sweating, rapid breathing. His blood pressure was 80/40 and his pulse was 110. What finally cured him was the doctor from the clinical trial arriving at the hospital and informing him that the pills he’d taken weren’t antidepressants because he had been randomised into the control arm of the trial. So he had actually overdosed on placebo. His belief that they were antidepressants had caused the same symptoms as if they had been. Within 15 minutes he’d stabilised.

Even the social is all bio. Poverty, discrimination, racism, poor housing, poor education,
inequality, loneliness, trauma, limited access to healthy food, all change your biology. They create a potent pro-inflammatory threat affecting the immune, circulatory, digestive, respiratory, reproductive, endocrine and nervous systems. And we know that inflammation is a driver of ongoing widespread pain, increasing sensitivity peripherally and centrally. We also know that the effects of this stress can be passed down through generations through epigenetic inheritance. It doesn’t get more complex than that.

“For doctors to truly identify and treat the underlying causes of ill health, they must begin by understanding how systemic racism and inequality contribute to persistent, harmful inflammation (a smouldering fire) in people’s bodies.”

*Inflamed: Deep Medicine and the Anatomy of Injustice*  Rupa Marya, Raj Patel

This is why it is so important to know the individual’s story and the whole complex picture. Often pain is an inappropriate response to a social threat and if we don’t understand this we can end up medicalising social issues. I’m thinking of the person who couldn’t walk downstairs, not because of any weakness or pain but because her ex-husband’s favourite pastime was to throw her downstairs.

The human body consists of a range of complex systems from cell to whole that all interact in complex ways, embedded in complex environments in an uncertain, complex world. We can’t separate these out. Our health, wellbeing, what we feel and experience emerges from this wider complex interplay of interwoven, intertwined, dynamic systems.

 We experience the world through our lived, whole body, embedded in information-rich environments and this is constantly changing.

When you consider the fact that the genetic material of the trillions of microbes that live on and within us is greater than our own and engaged in a dynamic, complex interplay with our own, it all gets a bit mind boggling. We are ecosystems; many ecosystems within ecosystems.

“It’s not about linear wiring. Brains are gardens, ecosystems.”

Rahul Jandial, neurosurgeon

The same could be said about us as a whole. I rather like the idea of tending to our gardens, our ecosystems.

“In complex systems you can test all the parts but it doesn’t mean

the whole will work.”

We need to move away from linear viewpoints and language that divide bodies, minds and context; to move away from structural explanations to explain pain, in order to embrace this complexity and to start thinking instead of how we nourish the ecosystem.

From a complex systems viewpoint pain can be seen as an emergent property\*, emerging in the complex conscious person (a dynamic whole) who is embedded and inseparable from their complex environment and uncertain wider, complex world when credible evidence of threat is perceived.

 The word perceived is important. It is an individual, subjective, personal experience. Context is vitally important. This is why it’s also not helpful to compare the human brain to a computer in the language you use because computers are indifferent to their surroundings. Context doesn’t matter for them. We should always consider the whole in context, in the knowledge that context heavily influences pain.

**The language we use creates and can change context in powerful ways**.

\*Emergent properties are defining qualities of complex systems,

The complex conversation

There is a complex conversation that goes on between everything within you, everything you do, everyone you meet, your environment, events in the wider world, past, present and predicted future. Even the things you watch on TV or listen to on the radio, go into this conversation including:

“All the things that you know, but that you don’t know that you know.”

Lorimer Moseley

The impact that pain has on people’s lives also loops back into this conversation to further change expectations. The words we use, the words society uses, our parents and teachers use all feed into this conversation.

 The problem is that we rather like things to be linear because they are measurable, have boundaries and make us feel safe. We know where we’re going with linear procedures and pathways to follow. We feel safer using mechanistic language like wires, gates, pathways but they promote a linear, dualistic viewpoint. In contrast the enormity of complex systems all interacting dynamically can be overwhelming.

­So how do we communicate this complex message in accurate, simple, respectful ways in recognition that there is a fine line between giving people enough hope to motivate them on a journey to a more fulfilled life and the best outcome possible for them, and giving too much hope which would create expectations that could never match outcome. And this will be different for everyone you encounter.

“The problem is not people being uneducated. The problem is that people are educated just enough to believe what they have been taught, and not educated enough to question anything from what they have been taught.”

 Richard Freynman

We have a tendency to repeat the words we have learned from our teachers and stick to them, often without questioning. These words can become so routine and familiar that we stop thinking about their effect. There is also a tendency to use short snappy phrases without thinking about what they really mean, and importantly what they mean to the individual in front of you. Let’s take for example the phrase *your brain makes pain.* We can’t simply spout phrases like this without thinking about how they may be interpreted, like this is one that’s often interpreted as ‘you think it’s all in my head’. And when you really think about this phrase, it could be considered dualistic so I would also question it and suggest we start thinking more along the lines of: “We need a brain to feel pain, but pain is made by the whole person embedded in their environment in that current moment within the added context of their past, present and future prediction”.

A person’s pain is very much tied to their story. When you know their story, you get an understanding of why they are in the place they’re in. So it’s not a question of learning a string of catchy quotes. We need to tie our words to the person’s story and their understanding, and always bear in mind that what’s routine for you is often a big life issue for your patient.

Setting expectations

The language we use sets expectations, and we know that expectations play a big part in the pain we eventually feel… or not. So we as clinicians need to keep asking ourselves:

“*What’s it doing to their biology? What’s it doing to their garden, their ecosystem?”*

These are some of the things people I have worked with have been told: –

 *“Now what is it that makes you feel the need to be unwell… my dear?”*

 Said to a lady with ME.

(I’ve observed that people who live with fibromyalgia and ME/ chronic fatigue syndrome tend to get more of this type of language, and I wonder if this reflects a clinician’s lack of confidence in being able to offer anything that will help. It also got me thinking if women are more likely to be spoken to in this way but that’s a much wider debate. Incidentally, this was a female doctor speaking to a female patient.)

 “*Dress for your disease, my dear”*

Said to a lady with RA when she had difficulty doing up buttons.

 “*Basically your father’s head is falling off.”*

 Said to the daughter of a man with dementia who wasn’t able to hold his head up.

 “*I don’t know why you’re so worried. You already have a wheelchair.”*

 Said to a lady with long-term pain who broke her ankle and was worried that it wasn’t

 healing as it should.

 “*Your spine is like a digestive biscuit dipped in tea.”*

 We’ve all heard variations of this.

Then you have the more subtle:

 *“You have to stop gardening.”*

 I’m happy to say this lady is back gardening and enjoying it.

This language doesn’t exactly nourish the garden, does it?

  *“Rest until it calms down.”*

 I once met a person who had been in bed for 40 years following a minor back injury at the

 age of 18. They were still waiting for it to calm down.

Then you have this type of language that’s used routinely…

 *Wear and tear, bone on bone, damage, degeneration, crumbling, soft, unstable, crushed,*

 *pinched nerve, vertebrae out of line, slipped disc, entrapment, it’s a rattler.*

(‘It’s a rattler’ was new to me until a couple of weeks ago. Those of you on twitter may have seen the discussion after it was seen in a letter describing an MRI scan of a spondylolisthesis. It was a real head in hands moment for me.)

Words like this can immobilise a person. They increase fear and anxiety so why are we so surprised when people are afraid to move?

“*We can’t fix or cure your pain. I’m sorry but there is nothing more we can do for your pain. We will be teaching you coping skills to manage your pain, learning about self-management. It’s about learning to live with pain.”*

What do comments like these do to a person’s resolve, to their expectations of their future life? Do they become a self-fulfilling prophecy? Do they play a part in prolonging pain? Why would someone embark on a long, often difficult journey to recovery if there is no hope?

Then we make things worse by combining language like this with high doses of medication.

“When you are told there is nothing left to do, you don’t look any more. After so many disappointments, you give up caring. When the medications steal your drive and your function, you plod ever onwards not seeking change.”

 Niki jones

As Niki says - when the language holds no hope, and the medications steal your drive and function you plod ever onwards, not seeking change. Life becomes a question of survival, a struggle to exist from one moment to another. Is this combination of hopeless language and high medication responsible for facilitating a state of helplessness?

Providing Realistic Hope

One of the biggest barriers we face is the ingrained belief that nothing can be done for long-term pain. All that’s left is managing or coping with it. It’s my opinion that this belief in itself can drive ongoing pain. But change is possible and it’s not just the person living with pain who needs to believe this, clinicians do too, because those seeking your help see it in your eyes and body language and all those little signs that people pick up on. Those who have recovered from pain have had to work at it…often over a long period of time, often without support and sadly often receiving negative feedback from clinicians because clinicians themselves don’t believe people can recover.

A friend of mine recovered from CRPS and her consultant told her, “*People don’t recover from CRPS. It may be in remission but you should prepare yourself for it to return*.”

Does a statement like this make it more likely to return?

Instead of “*We can’t fix or cure your pain. I’m sorry there’s nothing more we can do*.” what if we were to say something like this instead. “*There isn’t a quick fix but with perseverance, patience and courage change is possible and we’re here to support you on that path”*

This can all be backed up with facts about plasticity. Your nervous system and biology are changing all the time in response to your experiences and environment. Our biological systems aren’t just capable of change; they were designed to change. We can learn to nourish this process. I don’t understand why we’re not shouting this from the rooftops. Even as you sit there you are changing – your nails and hair are growing, your cells are being replaced, your last meal is being digested. Life is change.

 Learning that change is possible is vital for recovery because you need to believe that change is possible for change to happen.

“If i know anything it is how vital that alteration in belief from being ‘broken’ to being ‘self-fixable’ is – that with neuroplasticity and effective (hopefully supported) self-management, recovery is possible, and certainly a life better lived despite pain.”

Niki jones

And this can be a real game changer for people. It gives hope based on fact.

I like to think of pain on a continuum that we all slide up and down on. However, there are some people who are born without the ability to feel pain who are stuck at the lower end who sadly don’t usually live long, and others who get stuck at the higher end where their lives are
dominated by pain. So when we come to the question ‘can you cure my pain?’ the answer is no, because if we could cure pain we would die. We all need pain to protect us and to survive but we need to be able to move up and down this line for it to work appropriately. The same applies to stress, anxiety and fear. In the right context they are protective; in the right context they have saved our lives throughout evolution and continue to do so. They all have the potential to help or hurt.

Perhaps we could look at recovery as a process of getting unstuck and regaining the ability to slide up and down this continuum, beginning by noticing that actually you can do this,
because often a person living with pain won’t notice those moments when pain is less.

“*I’m not as stuck as I was.”*

This realisation gives hope, changes expectations and loops back to change the conversation further.

More bad language

So let’s take a look at some other phrases that are commonly used:

*Hurt doesn’t equal harm*

This could be considered as quite a linear statement. What we actually mean by it is that the

pain /hurt in your knee doesn’t mean you are harming / damaging your knee when you move it. It’s safe to move, and that’s a good message. But it needs expansion to clarify this because I think people know deep in their subconscious that long term pain is harmful to them in many ways. It may not be a measure of damage to a joint or tissue but the impact that pain has on their life is hugely damaging, socially, to relationships, careers, mental health. And that little voice in their heads will be nagging away at this. It’s all about considering that wider complex picture again; when you start to ‘get’ the complexity you begin to really understand that pain isn’t an accurate measure of what’s going on.

*Danger signals*

In an attempt to avoid using the term nociception people have simplified it to danger or alarm signals. I prefer to use the term alarm signals because calling them danger signals implies that they have already been assessed as dangerous, which they may not be, and you can then move on to an analogy with a fire alarm that becomes over sensitive and goes off when it doesn’t need to. It evolved as a warning to either do something: to take your hand away from the fire, or to stop doing something like walking on a broken leg. But alarms sometimes get stuck.

(Note too, that even a change in font and colour makes you perceive things differently. Advertisers have understood this for years. Those using hypnosis often ask people to visualise changing the colour and shape of their pain. Right at this moment you all have lots of nociception coming from your bottoms because you are sitting on them constricting the blood vessels and other structures. You’ve been unaware of that until I’ve drawn your attention to it. At this moment it’s not dangerous but it will become so if you don’t move for a long time.)

*Pain system*

I don’t use the term pain system because pain is the ‘thing’ that emerges from this conversation. It’s the alarm or nociceptive system, within the complex interplay of the whole person in their lived world, that gets stuck.

Other no- no words include:

*Pain receptors, pain fibres and pain pathways*

*Wear and tear*

What if we used something like ‘normal wear of age’ instead? We can use information from MRI findings of people with no pain to support this. We do ‘wear’ with age – it’s normal and nothing to worry about. We need to promote understanding that the spine is a robust structure, bones and ligaments are strong, and the body has a remarkable capacity for self-repair.

“We in the west have accepted the belief that our backs are fragile, with discs on the verge of slipping and nerves just waiting to be pinched, all held together by crumbling bones*.”*

Monty Lyman: *The Painful Truth*

Does this language nourish your garden, your ecosystem? We can get across the same information using different words.

*Pacing*

We could use activity planning or baselining. Baselining is a term I got from project management in business. It’s a point of reference and involves:

* Making a plan to set your direction
* Taking into account your available resources (financial, social,
 support)
* Agreeing to stick to this
* Regularly checking the viability of your plan in recognition that circumstances may/will change
* so ensuring that your plan fits your specific needs and your real life. It involves finding your baseline of activity or safe foundation from where you can begin to improve, taking into account that bigger picture. It gives a sense that this is a starting point from where you can nudge up changes across a range of things in order to change that conversation and bias it towards making less pain. It changes the focus from one of symptoms limiting you and obliging you to pace your life to one of moving forward.

In Tai Chi we talk about *Soft Limit*, which is learning to move and live life to the limit of your softness, so as to not over-extend yourself but also not hold yourself back or
restrict yourself. I think it’s a much kinder phrase than pacing.

*Coping skills*

How about using *‘skills to enable you to live a fuller life’* instead? “I can learn skills that will change my biology” is more motivating than ‘”learning coping skills ”. The realisation that I can actually, learn skills that will change my biology, and can change this conversation is powerful. It changes expectations, and therefore, that conversation. It gives hope.

*Self-management*

Perhaps we should focus instead on self-nurture, self-care, self-growth. Tending our gardens our ecosystems.

*“You have to be in a healing state in order to heal.”*

This simple and seemingly obvious statemen has had a profound effect on my thinking.

Warmongering

The use of warmongering language to describe our ‘battles’ with pain or diseases like cancer does nothing to promote a healing state. If you’re living in poverty, lonely, struggling to make ends meet, to keep a roof over your head, being discriminated against or bullied – all those social issues – you won’t be in a healing state.

*Enemy, battle, fight, damage, fear, destroy, pain killers, magic bullet, Dr’s orders, trigger points, shooting, burning, stabbing, beat, eradicate, cohort*

These are hard words of war and suffering. This type of language does nothing to promote healing. We even talk about drugs as pain killers, as weapons, magic bullets. I do understand that it can be motivating to want to ‘fight’ a disease, but take a moment to think about what it is you’re actually fighting – it’s your own body.

“People don’t die because they lost their battle with cancer. They die because we don’t have treatments to cure them. I didn’t choose to have cancer. If it kills me it won’t be because I didn’t try hard enough… saying people lose their battle with cancer makes a mockery of everything they went through before they died.”

 Liz O’Riordan, breast cancer surgeon ( living with cancer herself)

People don’t lose a battle with disease. Are we saying that people who die from cancer or live with pain are losers? - that they haven’t fought hard enough? They certainly aren’t weak,

and actually it’s an unwinnable war because we all die eventually, so are we all losers?

And with this mindset medicine always loses.

 It’s not about fighting, fixing or curing, it’s about facilitating change, it’s about nourishing your ecosystem. .We need softer words to heal. It’s not about being ‘strong’ it’s about feeling safe to let our guard down, to take our armour off. It’s about creating a state where healing can take place, tending to our gardens.

We also use dehumanising words which encourage us to look at the labels rather than the person:

*Pain patients, ‘how’s the back’ ‘I saw a difficult knee today.’ ‘I hate seeing patients in town’ ‘frequent flyers’ ‘bed blockers’ ‘fibro patients’*

These aren’t ‘difficult’ patients, they are people with complex problems. They want to be seen as a person of value not a list of symptoms or medical labels. It’s always good to remind ourselves that we could all end up there. It shouldn’t be a case of us and them.

*Resilience*

We hear a lot about improving resilience and this is ok up to a point, providing that we take great care to know the person’s story and that the sole onus isn’t loaded on the individual. Even the most resilient person has a point where they’re unable to cope, where they have nothing left when events or conditions outside their control become too much. Many of those who seek our help carry significant life burdens outside their control.

“What if a “fully staffed” hospital meant there was sufficient staffing to allow sick leave, mental health care, and parental leave without straining the system? What if that was resiliency?”

 Dr Jared Rubenstein, Palliative Care

This should resonate with clinicians who are being told to attend resilience training courses to prevent burnout when it’s the system that’s at fault. Often it’s the systems that need to build resilience, not the individual. Again we need to look at the much wider picture.

“ We have to stop blaming the individual, the whole – “it’s the individual’s fault” thing which completely ignores all the societal, political, systemic, structural etc contributors, including medications/over medications, food deserts, lack of access to nutritious foods, poverty, discrimination, racism, sexism and low literacy (a system failure, not an individual one”

 Joletta Belton, pain patient

.

*Goal Setting / SMART goals*

You might be surprised to see goal setting on my list of bad language. We should be mindful that those who have many external, complex pressures in their lives have no control over these, so any linear drive towards a goal will be interrupted by life events outside their control, which can make them feel despondent and helpless so they give up. .As Joletta said, – it’s not the individual’s fault. People don’t ‘fail’ at a treatment, at physio. It may not work for them, but **t***hey* don’t fail.

But we do need a direction… a purpose in life, so I like to talk about *setting a direction or a purposeful pathway.*

Language has a greater impact coming from the expert

“*Ahh – but that doesn’t apply to me. My consultant said I had two vertebrae out of line crushing a nerve.”*

I was having a discussion with someone about the benefits of movement and this was their reply. Just think for a moment, what does ‘vertebrae out of line’ actually mean? What happens to the spinal cord in this scenario? When a back ‘goes out’ where does it go?

Psychologist : *“We’re not here to fix or cure your pain. We’ll teach you coping strategies to manage it and learn to live with it.”*

*Pain consultant*: *“The medications you’re on are killing you. They will kill you if you don’t stop taking them.”* When this person said they didn’t want to stop their medication the consultant said ‘*well in that case we can’t do any more for you’* and discharged them.

Surgeon: “*My dear, it’s unforgiveable that you’ve had to suffer in this way. I can operate to fix this.”* This person’s life is already hugely challenging. The reality is that they’d declined because they were terrified because their pain was already unbearable. I’ll let you guess which option the person chose with catastrophic results down the line.This also highlights how important it is that the messages in our language are consistent across the board.

“You can always cut things out, but it’s the person that’s left that matters.”

Rahul Jandial, Neurosurgeon

How do we get surgeons to change their language? Perhaps the best way is to appeal to their egos because to be the *best* surgeon you need to focus on the person, to be an expert in people and their stories.

“Surgeons are known to focus more on the technique than the person but you have to be an expert in people and their stories. To be the best surgeon. It’s more than something technical. They read your energy, your eyes.”

 Rahul Jandial

Hope

Hope isn’t a word we hear much of in the world of pain, but complexity gives hope because it gives us many avenues in to influence change and having even just a glimmer of hope is so important, it changes expectations, biology. It nourishes the ecosystem.

 “No one has no potential to improve”

 Andrew Huberman

If you focus on nourishing the ecosystem, there is always something you can do to improve, whatever your starting point, and there will always be something we can do to guide them. If you talk about pain emerging from a complex conversation you can start thinking about doing more of the things that will bias the conversation towards making less pain. Things they can focus on, can do.

 Consider things like introducing fun, play and laughter.

Developing curiosity and creativity, feeling a sense of awe, spending time in nature, learning new skills, keeping a gratitude diary are all important because they expand that experience base from which the brain gathers its information. They change perspective, open up the world. They encourage the biodiversity of the garden / the ecosystem.

So rather than focusing on that big end goal of ‘fixing pain’ you’re focusing on the things that can not only bias that conversation to making less pain but that can make life better and healthier in the process.

To use a cliché, it has to be about the journey, not the destination, because the journey is your life and people need ongoing support on this journey.

“I don’t know where your journey will go, but you’ll never feel stranded.”

Rahul Jandial

Imagine if we could also say something like this? The way we work needs to change so that you can say with confidence *“You won’t be abandoned on this journey. We’re here to support you.”*

Ongoing support groups make this possible at low cost. They leave pathways of communication open and provide an ongoing background sense of safety and stability, an anchor. Simply knowing that is there can change that conversation

*“*You’ve got a posse. If you’ve got a posse an impossible situation

 becomes a challenge that you can rise to.”

Steven Kolter: *The Art of the Impossible*

For some people, support groups may be the only consistency and stability they have in their lives: the only safe place. They provide a regular safe space to help ease the load of all those life issues that we can’t deal with clinically. They provide ongoing hope.

 The belief that nothing can be done has become so ingrained that it can make us fearful of even suggesting there may be hope, and change can be made.

So we mustn’t lose sight of the facts that

* Complexity gives hope
* Change is possible
* The language we use can bias that complex conversation toward making pain … or not
* The language we use can nourish their ecosystems and the biodiversity of their gardens … or destroy all hope
* The language we use can play a big part in getting our biology to work with us not against us.

And it really is time to talk about how we talk to people about pain.

<http://www.betsan.org>

**Tai Chi Movements for Wellbeing trainer**

**AUTHOR:**

Knit for Health & Wellness. How to knit a flexible mind and more [www.knitforhealthandwellness.com](http://www.knitforhealthandwellness.com)

 **DIRECTOR:**

Stitchlinks – [www.Stitchlinks.com](http://www.Stitchlinks.com)

Institute of Therapeutic Craft and Creativity – <https://therapeuticcraftcreativity.com>

FlatBear

Discussion

*I have had neuropathic pain for about 8 years. I totally agree that the words that we use affect our expectations, and through that the pain we are going to feel. You said you didn’t like the word fighting when talking about pain but it is actually a word I choose to use when I think about my own pain. The word I really don’t like is pain ‘sufferer’ which is quite passive. I define myself as a ‘fighter’, which is more empowering and I get strength from it. My choice is to fight the pain that I am in on a daily basis rather than suffering it. So I actually like the word and I would be interested to hear from other pain fighters if there are any here.*

I think it’s important to use the words that work for you. But I think what happens when you think about fighting the body triggers off a stress response which prepares you to fight which increases tension etc. I really do get that you instinctively want to fight it because fighting is the kind of language that society has used for a long time; we fight what we don’t like which becomes the enemy. .

*Your comments don’t just apply to pain but to all sorts of illness including, for instance, progressive neurological conditions. You covered the subject so well and misuse of language needs to be dealt with by the medical profession.*

*I agree with everything you said, especially your comments on the adage that pain is what the person says it is. We’re all individuals and that’s why there is no one size fits all.*

 *If I can come back to Charles’s comment about fighting: I agree that it’s what works for an individual, but for me, fighting as I did for many years is too exhausting. I eventually came to a realisation that I was fighting myself and that my best option was to accept that nothing had changed and I was likely to have pain for the rest of my life in some way or another, and I had to find a way to live well with it. Once I stopped fighting it I began to see some improvement.*

*I agree that fighting feels less passive than lying down and taking it but for me my recovery started when I stopped fighting the pain. Letting go like that is one of the bravest things you can do.*

*I too fought for a long time – fighting was my profession and I was constantly in that fight or fight mode with everything I had and it was disastrous. But about five years ago I found I couldn’t sustain it any longer. I too got to a place of realisation that I was fighting myself and the pain was part of me and who I was at that time. But I didn’t want to be passive and never considered myself as a ‘sufferer’. I needed to ascribe to myself what my experience needed to be but not what it was. I wanted to be in control and be a more active person. So for me it morphed from fighting to learning to live to alongside my pain and accepting it as part of my human identity, instead of fighting that reality. It’s different for everyone but for me it worked; instead of being in a constant state of alertness I learnt to be kinder and more compassionate with myself.*

When I started running a course it was called wellbeing for people *in* pain but halfway through we changed it to wellbeing for people *with* pain. It was actually one of the participants who said “If you talk about being in pain it makes it bigger than me but I am a person living with pain and I am bigger than it”. I have used that word ever since.

*The thing I have found so frustrating is that I am being treated several people for each of my individual pains: one for spinal stenosis for which I had surgery, one since I broke my ankle which pivots on a pin; nobody sees me for fibro and CFS but I do see someone occasionally for my arthritis. They each tell me something different. For people in pain that is often why we feel the need to give up because we don’t get a consistent message in language that we can understand. There is a lot of technospeak which you were alluding to; but a lot of people don’t even understand what self-management or pacing are . If you have fibromyalgia you are told ‘we can’t do anything for you’. In our area you cannot be seen at the hospital if you’ve got fibro because their attitude is that they can’t do anything, so you have nowhere to go. If the medical profession want us to help ourselves there needs to be a lot more consistent language which can be understood by people with no medical training.*

One of the other problems is that people see different specialist clinicians all the time and these days you don’t even see the same GP, and nobody who has seen the overall picture. I remember one woman in her early thirties who had twelve different medical labels and twelve different specialists doing twelve different tests, advice and medication, and none of them talking to each other. I was fully aware of the core issues for that person which nobody had done anything to address.

*We’re not looked at holistically; we are seen as a list of labels and compartmentalised*

*Modern medicine is struggling to deal with persistent pain because if you train to be a pain specialist you stay in this one field, the same as a neurosurgeon, trying to find the silver bullet which doesn’t exist. The biopsychosocial model has its limitations but pain is all-encompassing. I used to think before my pain started that I could go to a doctor and they could fix any ailment but although you need medical input it really starts with empowering the person in pain to make incremental changes in their everyday life. We need to educate people with pain that the expectation shouldn’t be for the medical sliver bullet*

I agree but how can we go about that?

*It does need addressing in medical schools. So many of us have said the same thing about language; but health professionals have got so used to using ‘bad language’ (like crumbling disks and ‘crumbling toe joints’ as I was told) that they don’t realise how damaging and terrifying it can be. And that is all you hear and anything after that goes right over your head.*

I think education about pain needs to start in schools

*It can be just misunderstanding. My dad broke his arm recently but despite some nerve damage his pain level wasn’t too bad until he saw the consultant who said ‘it hasn’t healed ? properly?’ [word unclear on recording] . What he meant was that it didn’t look like it used to but my dad interpreted that the fracture was still ? ‘live’? and his pain went up for months just because of that one comment until he saw another consultant. So you have to be sure what the patient is hearing.*

It is so important when you [consultants] are writing to GP’s and copying in the patient to make sure that everything in it is explained to the patient and there is nothing new in it. I spend a lot of my time ‘translating’ letters which they don’t understand and often there is something in them the patient hadn’t known about before. Only last week I saw a letter in which the last sentence said ‘we have had patients with the same condition who have sadly not made it’. You can imagine the distress this caused. You have also got to think about the message on your clinic answerphone, imagining what it is like to hear it multiple times when you are in a lot of pain or feeling very poorly.

*Recently the Royal Colleges have advised that we direct all our letter to the patients rather than the referrer\*. It seemed difficult at first but now I prefer it. It makes one think more about the language you use. I wondered if an of the patients here had received such letters?*

*I was thinking about changing culture and we were talking about educating doctors. Making it part of training kind of presupposes that this sort of education will spread out from the medical profession in some way; and it’s quite autocratic to suggest that doctors are going to educate the public. We do need a cultural shift in the way people view chronic conditions including pain. It’s a very wide subject and involves social media. I don’t have all the answers: there are things going on in a small scale with patient groups and patient/health professional groups. II am preaching to the converted with the people here who will hear what you are saying but we have to put these ideas out there to everybody. But perhaps we can’t expect doctors to start doing it as we are quite conservative profession and you may have to drag doctors along rather than expecting them to lead.*

\*[NHS England » ROAN information sheet 23: Quality improvement: best practice for clinical letters](https://www.england.nhs.uk/medical-revalidation/ro/info-docs/roan-information-sheets/quality-improvement-best-practice-for-clinical-letters/)

[‘Please, Write to Me’ – guidance from the Academy of Medical Royal Colleges – Improving medical education and practice across the UK (wordpress.com)](https://gmcuk.wordpress.com/2019/03/14/please-write-to-me-guidance-from-the-academy-of-medical-royal-colleges/)

*[partly audible contribution from the USA] I am both a pain nurse and a person with chronic pain… my health system … insurance … accessing doctors notes electronically … very helpful as there may be something I have missed during the conversation. I can access all my lab reports and imaging and I find it very helpful … I don’t know if this is common throughout the US.*

*One of the tests I’ve got for consultation is that before the patient leaves the consulting room you ask them what their understanding is and what they have got from it to make sure that they have understood the message you have been trying to give them.*

*How we get the message out is a very interesting question. It’s not just the language in the healthcare encounters that matters but the language we are hearing everywhere: the TV shows we watch and the things that we read. Change in our collective understanding of people living with pain have to be a part of that. A lot of the campaigns in the public arena only involve the experts and don’t include people in pain. Instead of teaching health professionals and hoping that it will trickle out we need to start education much earlier … even before people get chronic pain so they have a better understanding when they do, which will help all of us in the long run. It’s a big ask for health professionals to step back and consider more social solutions …*

I agree and I think we can do a lot through support groups. I was running two before Covid and I think I learnt more from them than in any other way. I remember a discussion in one of them with a couple of people who were asking why they became more immobile in the winter. We have a tendency to assume things about people; I suggested the obvious answer that they weren’t getting enough exercise but it transpired that it was in fact because they couldn’t heat their homes so they were either staying in bed or spending their time wrapped up in sleeping bags on the sofa. We have to make sure that people are aware of such wider issues

*A lot of people have found that the first response to seeking help with their pain is to comment on their weight, so they immediately turn off. There is no doubt that if you are overweight you put more pressure on your joints and ligaments etc. and of the value of healthy eating, but as you have been saying doctors don’t take into account the backstory; some people don’t know how to cook or can’t afford healthy ingredients [or have been comfort-eating as a response to stresses in their lives including the pain. Ed.] If the first thing they hear is “your pain will be better if you lose weight” they are not going to hear anything else. If they perceive that the clinician doesn’t realise how distraught they are they are going to lose any respect for them.*

*It was only when I came off opioids that it was explained to me … I was 25 stone and it wasn’t for the lack of trying to lose weight; I wasn’t sleeping, I wasn’t moving … it was all working against me especially the cocktail of meds I was on. Once this was explained it made a lot more sense. We don’t need judgement - we need help and understanding.*

That kind of comment isn’t even correct as often if you lose weight the pain is still there. And a lot of people I work with consume a lot of high sugar fizzy drinks because they are so tired and fatigued as they don’t sleep and try to boost their energy this way. It’s all part of that wider picture.

*You have made the point that language is incredibly powerful and you don’t get enough contact between patients and clinicians. Different takes on language such as fighter versus non-fighter need exploring in a clinical context. We need much more contact and support and the sort of model you have in StitchLinks. Doctors working with patients outside a strictly clinical model is incredibly important because I can only see medicine becoming more fragmented. Somebody commented earlier that they are not looked at holistically but I fear that that is highly unlikely ever to happen, so we should be using resources like this and a whole range of other things to help people with chronic pain to get the help that they require to interpret and explain their problems in a way that they can understand. You have opened up a huge area.*

My interest in pain started in 2005 when I started researching the therapeutic benefits of knitting and set up a knitting group linked to a pain clinic. I was sent patients that they couldn’t do anything for. Over the years I got to know all these people and their stories. None of the clinicians had never heard their stories, but these were so relevant to their condition and their treatment and actually sometimes explained why their treatments weren’t working. Once the stories were known things began to change. That support groups and others I ran were so important for people who knew they had somewhere to go to where they could ask questions about their pain and we talked about every other relevant subject and aspects of their lives.

*What Betsan has been saying to this audience is to some extent preaching to the converted, but the important and difficult thing is to evangelise this message to the heathen who have done so much damage with their misuse of language before they come to see us. I really don’t know how this is going to be achieved but I would be interested to hear from those of you who work in teaching hospitals whether students get lectures on this subject and if not why not.*

*There is a programme which is being rolled out in medical schools by the Pain Society and the Royal College of Anaesthetists.. How effective it has been I don’t know…*

*… Specifically about the use of language? …*

*I think it is covered. I don’t think it is just about pain: if we talk about areas like dyspnoea, chest pain and angina, or arthritis, for example, there are huge implications for the use of language. It should be a major part of humanities within medicine.*

I think we could learn a lot from hypnosis …

*… absolutely. Hypnosis is just using words – it’s all about language and choosing the right healing words. It’s not complicated but it seems like another universe which doesn’t connect with conventional general medical training. We have had a series of RSM sessions on hypnosis over the last six months.*

I think there is almost a fear of using healing words. When I was introducing therapeutic knitting into the medical world I had to call it something scientific like bilateral rhythmic psychosocial intervention for people to accept it.

*I would like all health professionals to have a better understanding of the use of language because the nocebo effect is much more powerful than placebo. People who go to see a doctor are frightened and stressed and already in a state of trance and the body automatically hears the negative. Regarding fighting vs. passive suffering: when I was a GP used to tell patients “it’s about using the right part of the brain; there are things we cannot control. If someone is having a panic attack and you tell them to pull themselves together it gets worse, not better. If you are constipated and want to have a bowel action the harder you try the worse it gets because your autonomic, your limbic system which is dealing with the functions of the body on your behalf in the background so trying to control it is not going to help.*

 *The other thing I used to say was that doctors are trying to find out what is wrong but in 50% of the patients that come to you as a GP you never can, and they just get better on their own. But this applies to pain of no underlying cause; if you’ve got rheumatoid arthritis the situation is more complicated …*

*From a US perspective there are data on how much pain is covered in medical schools and it’s a matter of hours and pretty minimal, just a lecture of two. Secondly, if doctors can rule out cancer or broken bones, other than that they are left on their own. I don’t know of any questionnaire or survey instrument that looks at these other factors. Doctors only have 15 minute appointments. I don’t know how to overcome such things. In articles about incidence of chronic pain sufferers are displayed on histograms divided into decades: it seems to peak around the late 40’s and people don’t have so much in later life. I don’t know why.*

 *I hope in this group we can figure out next steps. We are all on the same page; this has been tremendously instructive, particularly listening to the chronic pain patients, but I’m not sure how we can tackle this.*

 *I want to come back to the awful damage that has been done; this isn’t about apportioning any blame to GP’s or consultants, and what has happened has happened and I don’t hold any malice towards anyone I have met on my pain journey. But we do need to figure out how to move forward.*

 *You expressed some dislike for the words ‘pain-killers’ What do you suggest as an alternative ?*

 I prefer ‘pain-relievers’

*In the past I have talked about killers but I realise that it is a harsh and aggressive word and I think that ‘preventers’ might be better with the idea of using them pre-emptively; but someone said in the chat that from her point of view she didn’t like it as it doesn’t really describe what they are going to do. As to the language we use to patients: everybody is different and the words we use to one patient might not be appropriate for another. So I tend to ask people what terms they would like to use so that we are kind of on the same page.*

 *With regard to training: I have an undergraduate degree in [?] and a master’s in pain management but when dealing with people with chronic pain the thing I don’t feel equipped for is the mental health side of it; so I’m looking for courses in that. But a lot of the time people are experiencing ambiguous loss: they are grieving as they don’t feel like the person they used to be and can’t do the things they used to do. People say “ I can cope with the pain, but what I can’t cope with is the loss of all the things I am leaving: my social interactions, being able to get out of the house and the consequences of that. I find that if I have patients with physical illnesses and positive scans and things they can get a lot of support from mental health teams, but if I see someone with idiopathic chronic pain or fibromyalgia it is very hard to get support.*

I see points from the chat: 1: suggestion of just ‘pain medication’. 2. ‘Pain killers gives unreasonable expectations and you might be tempted to increase the dose just to fulfil such expectations’. And we know that expectation plays a big role in placebo and nocebo and the pain we feel.

*Instead of raising expectations when we prescribe analgesics by calling them pain killers perhaps we just should just say this is something that will take the edge off your pain and make you more comfortable. It’s such a tricky balance …*

I have found that one of the things that works for people in pain who are on many pills a day and they take them all in one go without really thinking about them, is to advise them to create a ritual around pain medication and thinking what each item is meant to be for; I have tried that with people and found that it actually helps up to a point. But a lot of people have absolutely no idea what all these pills are supposed to do.

*From my point of view as both a pain patient and a clinician I have an advantage as I understand my pain medication and that different pains need different drugs. .*

*There are wonderful packets of pain practice around, and a lot of us here who want to shift things in better ways. But how do you turn this into a movement? There are organisations, support groups, professional groups but is there something else needed? Is there something we can do to make it coalesce or do we have to wait for it to grow organically.*

It's difficult to answer that. I think that things have actually improved quite a lot in the last few years. We are seeing some change from the bottom up, as it were. We see more people living with pain getting involved and pushing change from their perspective. When they start working with clinicians we have a much stronger position to grow from and that is definitely growing; it’s working together, not us and them.

*So what is the next step?*

I would suggest getting the information on the BNPS website, and getting articles into journals.

*I understand the website is about to get an overhaul. There is a lot of it out of date and the Patient Voice Committee are getting charge of our own pages, and we will be publishing some patient stories. We are recruiting to the committee.*

There are also organisations like the Footsteps Festival online for people living with pain activities and events for them

*It’s a very positive thing. We are very mindful that want to show people all the different ways that we are living well with pain. It also features good science-based stuff including Betsan’s presentation.*

*On a smaller scale there are a lot of pain professionals with whom we share what we’ve been learning in or practice. I would be happy to share the recording of this session with people in my hospital and local ones if it is available to get that conversation started.*

*This will be possible and the transcription will be available on our page in the BPS website.*

*It’s a different area, but my partner has a serious mental health issue , and I was asked to speak to an audience of psychiatric consultants and nurses about my experience of living alongside someone who has problems 24/7 and I was surprised that they understood so little the daily challenges that this provides. They knew the science but didn’t seem to recognise how complex it was to have to constantly watch their moods, how they were reacting for instance to something on the television. I was asked if they had an insight into their illness; the answer is no because their reality and mine are poles apart. So perhaps with pain, maybe we need to take it upon ourselves to put this message out and perhaps offer to speak to our own GP practices about the experience and challenges of living with pain.*

*Maureen: you are very much involved in the Royal Society of Medicine. I haven’t seen anything advertised in their current series of seminars on the use of language with reference to pain and all the other things that doctors talk to patients about. . Do you have the means of suggesting that as a topic for a seminar? Can I suggest a possible speaker on the subject?!*

*Regarding hypnosis: it has such a lot of baggage such as stage hypnosis but it is an enormous resource for using peoples’ creative imagination to deal with their healing and moving forward from their suffering. And it’s all about words and language. Would the patient group in the Pain Society be interested in a talk about that?*

*I want to give a plug for the Global Alliance of Partners for Pain Advocacy (GAPPA)\* which started as a presidential taskforce for IASP but we are working towards becoming our own non-profit organisation. We are having our first conference in November this year along with our foundational membership guide* Footstep*s is going to be. The presenters are going include people in pain as well as clinicians and researchers. the object is to bring people, in practice, research and in pain together to collaborate in finding new solutions and moving forward Do you want to be a part of it? – I want to encourage everyone to become members!*

*\* https://www.iasp-pain.org/advocacy/global-alliance-of-partners-for-pain-advocacy-gappa/*

*Will there be national chapters?*

*Our foundational membership is going to open up in October We are looking to collaborating with IASP chapters and the BPS etc. Initially there will be a global membership and a community platform where everybody can come together; there will be resources and training available, and means of connecting people. We are looking for patient partners. People can join either as individuals or organisations.*

*Betsan talked about islands of good practice and a list of these would be wonderful.*

*Yes - we are hoping to get these together*

Points from chat

Medicine tends to reflect the cultural norms/values and has been very successful in areas that are linear and reductionist —Iain McGilchrist covers this v well and his videos are v good in terms of lateralisation and specialisation . Pain and complexity certainly needs an interactive approach which tends to be a bit counter cultural perhaps? Non-threatening language tends to be more of a dance than a script too … People who are in threat mode very often are running on mechanistic notions (I am a physiotherapist) and its usually necessary to go with this so timing of language is crucial too … However it’s as you alluded not all due to language at all so working holistically with the body (see today’s article in the guardian on trauma ) I think the key area here is soft limit and tai chi metaphors are ideal !!

What age pain should be taught in schools?

?Start teaching the simple pain science (including difference between pain and nociception) from Junior level maybe 7-8 upwards

 We can challenge the language our HCPs use to us - I keep doing so with my GP (not to much avail!) but my Taper team are much more responsive and are including me in deciding what language we use - for example we decided together to call my recent taper (fentanyl) hold a "therapeutic pause" as it felt much better than a hold, break or anything that felt like a failure. And it’s allowed me to stabilise and do the peloton ride! Valued activities are important after all...

Pain shouldn't discriminate geographically but it does - for example in the UK we report more pain than the average country because of the NHS and our belief and expectation that we shouldn't have to put up with any suffering

Pain relievers? I’ve not had any which have relieved my pain. My understanding of the word reliever is to put it so far in the background that you almost don’t feel it! Comes back to checking what the person understands by a word!

Early intervention, multifaceted interventions, therapeutic relationships, avoiding nocebo effects, social prescribing etc. all so important. Great presentation and fascinating discussion.